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How to involve cancer patients at the end of life as co-researchers

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The importance of user involvement in the organisation and delivery of health services and the conduct of research has increased over recent decades. Involving people at the end of life in research remains an under-developed area of research activity. The Macmillan Listening Study, a UK-wide study exploring research views and priorities of people affected by cancer, adopted a participatory research approach. Patients and carers, including two participants receiving palliative care services, collaborated in all aspects of the study as co-researchers. In this paper, we discuss the experience of working with co-researchers to collect data from two hospices. We will discuss practical, ethical and methodological challenges, including specific training needs and the emotional demands of conducting the research. Recommendations are made to facilitate successful collaboration with palliative care service users in end of life research. *Palliative Medicine* 2006; **20:** 821–827

Key words: palliative care; patient involvement; patient participation; research; user involvement

Introduction and background

User involvement in the organisation and delivery of health services and in the conduct of health research, has steadily increased in importance over recent decades. The political imperative to involve service users in the UK is evident through recent Department of Health publications, such as *Choosing health* and *Our health, our care, our say*.[1,2] Similarly, the Calman Hine report,[3] and the NHS Cancer Plan,[4] both recommend a patient-centred approach to the organisation of cancer services.

Service users are also becoming more involved in the conduct of health research.[5] The suggested benefits of such involvement include ensuring that research questions, methods and recruitment strategies have utility and relevance, identifying issues that may be overlooked by 'professional researchers', and assisting in the dissemination of findings.[5]

It is now suggested that user involvement is part of good research practice. Research governance guidelines in the UK state that 'Relevant service users and carers or their representative groups should be involved wherever possible in the design, conduct, analysis and reporting of research'.[6] Governance guidelines also suggest that research participants should be offered the findings of the studies they are involved in. These guidelines are now part of the research ethics process. Question A10 of the Central Office for Research Ethics Committees' NHS REC Application form specifically asks applicants to 'Describe any involvement of research participants, patient groups or communities in the design of the research'.[7]

Strategies for user involvement are varied and exist on a continuum from the consultative level of steering committee representation, through collaborative, partnership approaches to research,[8] to 'user controlled' research.[9] Participatory research, in particular, has emerged as an alternative to the traditional perspective of a dominant researcher and a submissive research 'subject', and seeks to involve participants as active citizens throughout the research process.[10,11]

Little is known about strategies for involving people at the end of life in research, a situation compounded by particular practical, ethical and methodological challenges associated with palliative care research.[12] This paper, therefore, discusses techniques used in our study to identify, train and involve people at the end of life as collaborators in research. Whilst this paper describes the experiences of working with patients receiving palliative care services, reference will be made, where appropriate, to other patients collaborating in the study who are not receiving palliative care. This paper focuses, in particular, on the challenges of involving patients in end of life research, and makes recommendations on how they can be managed.

The study

The Macmillan Listening Study was initiated and funded by Macmillan Cancer Support and had two principal aims: to explore cancer patients' views and attitudes towards cancer research (eg, what do participants understand by the term 'cancer research'? what experiences, if

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any, do patients have in taking part in research?), and to identify their research priorities. Participants were recruited through 10 sites located across all four UK nations, including two hospice day care services. The identification of the research views and priorities of people at the end of life formed one component of this study. The study was informed by participatory research approaches and, hence, patients and carers collaborated with the experienced researchers as equal partners. This included two patients receiving palliative care services who volunteered from one of the two participating hospices.

Ethical approval for the study was obtained through the South East Multi-Centre Research Ethics Committee. Local Research and Development Governance approval was secured according to local requirements in each study setting.

Identifying palliative care patient co-researchers

Traditional means of identifying patient representatives, such as approaching patients through support groups, have been criticised for excluding often under-represented sections of society, such as people from diverse ethnic minorities, people with rarer cancers, and people at the end of life.[13] Consequently, we adopted multiple methods to identify patients and carers to collaborate on the study. First, patients and carers were identified through patient forums of UK cancer networks to form a 'Reference Group', who advised on the design of the study and related material (eg, Patient Information Sheets).[8] At the initial meeting, no person was receiving palliative care. Therefore, a more targeted approach was adopted where representatives were identified from the day care service of a participating hospice. It was necessary to collaborate closely with the clinical team at the hospice as they were able to identify two potential collaborators. A good working relationship with the hospice was necessary to allow effective collaboration and data collection.

Members of the reference group volunteered to become patient and carer 'co-researchers' and, thus, received training and support to collaborate with experienced researchers throughout the course of the study.[8] As focus groups were the main method of data collection, this entailed co-moderating the group with an experienced researcher. A total of 15 patient and carer co-researchers were involved in the study, of which two were the collaborators identified from the hospice day care service. A total of 17 focus groups were conducted with 105 participants, resulting in a mean of six participants per group. Two of these focus groups were held in the two hospices and involved seven participants in each group. Two co-researchers in receipt of palliative care services facilitated one of the focus groups, and two patient co-researchers not in receipt of palliative care services facilitated the focus group in the other hospice. The co-researchers receiving palliative care services collected data from the hospice they were attending and did not facilitate any other focus groups. This was because people receiving palliative care services are typically undergoing change, which many find stressful, and hence involving them at additional sites could generate stress. Furthermore, involving the co-researchers receiving palliative care services at additional sites would have increased the complexity of gaining ethics and R&D approval.

Challenges of user involvement

Involving patient and carer co-researchers in the study generated a range of benefits. The impact of their collaboration has been documented elsewhere,[8] but improvements include designing a more effective and accessible Patient Information Sheet and focus group question schedule, and using personal experiences and 'local knowledge' to respond to and prompt participants. However, the involvement of co-researchers also generated particular practical, ethical and methodological challenges, each of which will now be discussed.

Practical challenges

Appropriate and effective training is required to ensure that users become valuable contributors to the research process.[14] Training is effective where it is undertaken iteratively (allowing co-researchers to reflect on experiences of data collection during the study), and collectively (allowing co-researchers to share their experiences with others).[8] However, this was not practical for co-researchers receiving palliative care. As a consequence of their advanced disease status, the period over which they felt able to be involved in the study was limited in relation to other patient and carer co-researchers, as it was not possible for them to travel to training events. Hence, alternative training was provided to meet their specific needs. In addition, the co-researchers receiving palliative care services were unable to collect data from the second participating hospice, as it was situated too far away for them to travel. By contrast, other patient and carer co-researchers were able to participate in a series of focus groups and, therefore, gained more practical experience.

Successful training with co-researchers receiving palliative care services involved:

- Flexible training sessions:
  Training was provided both on an individual basis and in two meetings between the researcher and the co-researchers, arranged in 1 and a half hour sessions (in contrast to the full day given for other co-researchers), in order to limit the burden for co-researchers receiv-

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ing palliative care services. The experienced researcher structured the training in accordance with the wishes of the co-researcher, providing additional sessions if requested. All co-researchers had access to the research team outside the training events to raise any research-related queries. Mock focus groups were held for all co-researchers to gain experience and confidence in moderating the discussion. Table 1 summarises the content of the training meetings provided to co-researchers receiving palliative care services.

- Remote learning:
  Strategies were identified to allow co-researchers receiving palliative care services to learn from other co-researchers' without travelling to training events. This entailed listening to selected recordings from focus groups already conducted. In addition, articles and other material relating to focus group approaches were provided.
- Transport:
  Transport was provided by the research team for the co-researchers receiving palliative care services to enable them to attend focus groups and any training related activities. This necessitated members of the research team obtaining travel insurance to cover the transportation of patients in their car.
- Financial resources:
  Significant time and financial resources had to be provided to enable effective and flexible training. The two hospice day care consultation groups collectively took five weeks to organise, support and undertake. This time included travelling to participating hospices, discussions with hospice staff in person and via telephone, face-to-face and telephone discussions with co-researchers, telephone conversations with all focus group participants and moderating the consultation groups. This inevitably resulted in more time being occupied by recruitment and data collection than would occur if an expert researcher was solely engaged. For the co-researchers not receiving palliative services, attendance at training events resulted in additional costs, such as room hire, travel expenses and overnight accommodation. These costs are discussed elsewhere.[8]

Table 1 Content of training events for co-researchers receiving palliative care services

Meeting1
Practicalities
Gaining consent on the day
Recording equipment
The focus group
–Discussion
–Refreshments
–Activities
Feedback questionnaires
Focus groups
Why choose focus groups?
Focus group questions
Facilitating discussion
Working collaboratively
Tricky situations
Arguments
Distress
Personal disclosures
Talkers
Non-talkers
Meeting 2:
Mock focus group
Introductions
Reminder of structure of focus group
Part I: Practice of discussion (name labels, consent, introduction, initiating discussion)
Part II: Introduce activity (summary of discussion)
Part III: Activity (ideas, research questions, prioritising, conclusion)

In addition, there were practical considerations for the focus groups themselves. Due to their advanced cancer, one co-researcher had a limited attention span, whilst the other had restricted physical movement. It was, thus, necessary to ensure there was sufficient flexibility within the data collection process to respond to their specific needs. For example, the co-researcher with a limited attention span adopted the role of the observer. This was an important role as the observer records details, such as main points of discussion, emerging issues, the dynamics of focus group discussion (eg, dominant or reticent participants), and the quality of the discussion (eg, statements that are not adequately developed). In addition, the co-researcher had additional tasks, such as welcoming participants and assisting with focus group tasks, such as summarising the discussion and prompting the moderator. This minimised the need to facilitate discussion over a prolonged period.

It is recommended that users are involved in all stages of the research project, from initial design and recruitment, through data collection and analysis, to writing up and dissemination.[5] However, this was inappropriate for the co-researchers receiving palliative care services, as data collection for the whole study took 12 months to complete and both were experiencing physical decline and facing an uncertain future. In an effort to provide feedback, the experienced researcher co-moderating the groups informally discussed emerging findings and the importance of the data with the co-researchers.

Ethical challenges

The study adopted similar ethical principles for the co-researchers as those for the participants, including clear details of the nature of their involvement and an understanding that they could leave the study at any time without giving a reason. This was particularly important for co-researchers receiving palliative care services, as they needed to assess whether involvement was within their physical and emotional capacity. The emotional

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demands of being involved in research as co-researchers raised ethical issues. Typically participants discussed personal experiences and hearing such accounts could be potentially distressing for the co-researchers. Hence, it was necessary to ensure appropriate emotional support, such as clinical supervision, was available.

The co-researchers receiving palliative care services did not report being distressed as a consequence of moderating focus groups and, indeed, commented on the valuable and rewarding nature of collaborating in the study. Similarly, no participants reported any difficulty in having the groups moderated by a patient from the hospice in evaluation questionnaires distributed at the end of the focus group. However, from our experience, there were emotional demands placed on co-researchers not receiving palliative care services. There appeared to be a sense of unease in moderating groups with participants with whom they did not share similar experiences. This had to be managed sensitively through the professional guidance and support of the experienced researcher. In this regard, it cannot be assumed that co-researchers are at ease in conducting research with other patients on account of their diagnosis alone. For co-researchers with little experience of hospice settings, raising issues with participants receiving palliative care can be challenging due to a fear of asking inappropriate or potentially disturbing questions.

Methodological challenges

A total of 14 participants took part in the two hospice day care focus groups. These participants included people who are often under-represented in research: patients with rarer cancers and people at the end of life. However, as the general hospice population is typically under-representative of ethnic minorities, it is not surprising that only one participant was from a minority ethnic background. This imbalance was redressed to a degree in the study as a whole by conducting a series of focus groups outside the hospice setting with South Asian participants.

Participants in the hospice day care focus groups were known to each other and to the co-researchers receiving palliative care services, as they had attended the same day groups. This is contrary to recommendations that focus group participants should not be acquainted with each other due to the potential for upsetting the dynamics of discussion and inhibiting responses.[15–17] This is clearly not feasible or appropriate for focus groups held in palliative care settings. Groups held in this setting can, therefore, result in atypical dynamics, as is evident here where a co-researcher receiving palliative care services, Joanne, introduces the discussion (pseudonyms replace participant or co-researcher names throughout the paper):

> We are up and running. Good. So, some of you already know me, I usually attend the Monday meeting. Some of you know my colleague, who comes to the Wednesday group . . . I think we all know who we are. So, can we go around the group and just say who we are and which group we normally attend.

Hence, running focus groups where the moderator and participants are known to each other requires sensitive management of the discussion. The training must emphasise that co-researchers cannot direct questions solely to those they know and must not phrase questions in a way that assumes shared knowledge and, thus, excludes others.

It is also recommended that moderators should guide and not lead discussions or impart any opinion that may influence the discussion. However, for co-researchers who share similar experiences and are known to some participants, the barrier between neutral researcher and involved participant is blurred. This can result in tension for the co-researchers over their roles as researcher and participant:

> Mandy: What do we know about chemotherapy?
> Debbie: Nothing.
> Mandy: Not a lot.
> Co-researcher receiving palliative care services (Val): I have to say, if I can speak from a personal point of view, I know I'm not really supposed to, but from my experience of chemotherapy they do actually give you information before you start it, and they do tell you the drugs that you're taking and about their side effects as far as I know.

Involving patients as co-researchers inevitably exposes the tension between 'researcher' and 'participant', and the blurring of these boundaries is an important part of participatory research, one that can potentially enhance data collection through effective prompting and making participants feel more at ease.[10] However, there is a difference between sharing experiences to promote effective discussion, and actively steering discussion to reflect a personal agenda. Our experience reveals the importance of reiterating this distinction in training sessions. The above quote illustrates that the co-researcher receiving palliative care services uses personal experience appropriately to offer an alternative perspective and to stimulate greater discussion. However, the following example from a co-researcher not receiving palliative care services illustrates the problems associated with expressing a personal agenda, one that may be inappropriate for a hospice day care setting:

> Patient co-researcher (Penny): Can I just come in there? . . . a few weeks ago, I went to a conference . . . I stayed right to the end, because I really wanted to hear two speakers. One was a very famous researcher in epidemiology and has a particular interest in smoking

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and its effects on health . . . What they showed unfortunately was that the impact of all the research carried out had a very small impact on the effect in extending life . . . What would make a big difference is banning smoking in public places . . . So, I'm giving you the message that that's the thing that would change cancer deaths.
Nicola: Yes, but it's not going to help me.

This illustrates the importance of training to highlight the distinction between promoting and leading discussion. Furthermore, as focus groups are very much a craft skill, it highlights the need for piloting to allow co-researchers to gain experience in making this distinction.

In light of these challenges, a 'collaborative' approach to data collection proved to be effective. Through a shared code between the co-researcher and the experienced researcher (such as the raising of a hand), the co-researcher could indicate when they were fatigued or felt unable to continue with moderating the discussion. It also permitted the experienced researcher to provide a 'quality assurance', taking over the moderation where necessary to facilitate the depth of data. In the following excerpt, the experienced researcher uses her expertise to return to a topic rather than providing an answer to a question:

Co-researcher receiving palliative care services (Joanne): If you haven't been involved . . . What have you heard about cancer research?
Debbie: Not a lot.
Mandy: I was going to say, the TV adverts seem to be the only thing.
Co-researcher receiving palliative care services (Joanne): You don't really know what they have researched already?
Debbie: No.
Mandy: No . . .Co-researcher receiving palliative care services (Joanne): Perhaps Jane can give you some ideas of what already has been researched?
Experienced researcher (Jane): Actually, I was wondering if I could just go back to something that Mandy said. You suggested that you had seen something on the television. I wonder if anybody could think of any examples of something that they might have seen on the television?

Here, the co-researcher was working in an effective partnership with the experienced researcher, and this collaborative dynamic of 'co-moderation' maintained the quality of data collection.

Discussion

There is an imperative for greater involvement of service users, both in the organisation and delivery of health care services and in the conduct of research.[1,2,5] Guidelines for user involvement in research have tended to be general and, thus, often fail to detail the specific demands associated with involving people at the end of life.

The Macmillan Listening Study adopted a novel process for involving people affected by cancer as equal partners in the research process.[8] The novelty of the approach is particularly significant as it demonstrated that cancer patients receiving palliative care services can contribute to research by becoming active collaborators and undertaking data collection.

Involving cancer patients and carers as co-researchers in the study enhanced the research process in several ways.[8] The appropriateness of collaborating with people affected by cancer in research, and the extent to which they should be involved, is dependent on the aims and objectives of the study. In the Macmillan Listening Study, it was important that people often under-represented in research were given a voice and that participants felt at ease discussing a range of research issues rather than focusing on what they perceived as the interests of 'experts'. In this regard, it was appropriate to involve patients and carers in the design and conduct of the study.

Palliative care research is still an emerging discipline, and traditional research approaches, such as randomised, controlled trials, have often proved challenging to execute. In this regard, collaborative approaches offer an alternative approach, one that is sensitive to the particular needs of people receiving palliative care services. A collaborative approach also allows people approaching the end of life to inform research outcomes that are important to them.

Adopting a collaborative approach to palliative care research, however, does challenge assumptions of appropriate means of data collection. For example, recommendations that focus group participants should not know each other or that moderators should not express personal views to stimulate discussion are unachievable when applying a participatory research approach to a palliative care setting.

Involving patients receiving palliative care services as co-researchers does generate particular practical, ethical and methodological challenges. Consequently, the following recommendations can be made from our experiences.

Recommendations

1) The involvement of people receiving palliative care services in research should be supported where feasible and appropriate to enhance the design and

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relevance of studies and help ensure the needs of participants are met.

2) User representatives should be identified via various strategies rather than through a single approach, such as a support group, as members may be less typical of the general population. People receiving palliative care services can be approached directly through hospices. Identifying appropriate collaborators necessitates working with clinical teams and establishing good working relationships with participating palliative care services.
3) Extensive training needs to be provided to enable effective data collection. For co-researchers receiving palliative care services, training has to be flexible and tailored to meet their specific needs. Hence, training sessions should be short and held over successive days. 'Remote' learning should be provided to allow co-researchers receiving palliative care services to manage their learning in their own time rather than travelling to training events. Sufficient time and financial resources have to be provided to enable effective training.
4) Focus groups should be sensitively moderated to allow participants to discuss issues in a supportive, inclusive and confidential manner. However, given the structure of hospice day care services, focus groups may not be appropriate where the discussion is likely to yield sensitive information.
5) It is unlikely to be feasible to provide study results to co-researchers receiving palliative care services due to the unpredictability of their condition. Alternative means of informing them should be adopted, such as informally offering emerging findings.
6) Ethical guidelines for patients participating in studies must also apply to co-researchers. This includes being adequately informed about what involvement would entail and being able to leave the study at any time.
7) Emotional support should be provided for all co-researchers in the event that they become distressed as a result of their involvement. Support can take the form of counselling services or clinical supervision. Additional supervision and training support should be available to co-researchers not receiving palliative care services who may be concerned as a result of their unfamiliarity with such services.
8) A collaborative dynamic between the co-researcher and the experienced researcher should be adopted. The co- and experienced researcher should work together to ensure the quality of the data is maintained and the needs of the co-researcher are met. With focus groups, this means that co- and experienced researchers are equal partners in moderating the discussion.

Conclusion

There is currently great interest in involving patients and carers in the research process. Supporting such involvement with patients receiving palliative care services, however, generates practical, ethical and methodological demands. By managing these demands, it is possible to ensure that people at the end of life can become valuable collaborators in research.

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References

1 Department of Health. *Choosing health: making healthy choices easier*. Department of Health, 2004.
2 Department of Health. *Our health, our care, our say: a new direction for community services*. Department of Health, 2006.
3 Department of Health and the Welsh Office. *A policy framework for commissioning cancer services: a report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales*. Department of Health and the Welsh Office, 1995.
4 Department of Health. *The NHS cancer plan: a plan for investment, a plan for reform*. Department of Health, 2000.
5 Hanley B, Bradburn J, Barnes M, et al. *Involving the public in NHS, public health, and social care research: briefing notes for researchers*, second edition. INVOLVE, 2004.
6 Department of Health. *Research governance framework for health and social care*, second edition. Department of Health, 2005.
7 COREC. *NHS REC application form*, Version 5.1. Central Office for Research Ethics Committees, 2006.
8 Wright D, Corner J, Hopkinson J, *et al*. Listening to the views of people affected by cancer about cancer research: an example of participatory research in setting the cancer research agenda. *Health Expect* 2006; **9**: 3–12.
9 Turner M, Beresford P. *User controlled research: its meaning and potential*. INVOLVE, 2005.
10 Park P. People, knowledge, and change in participatory research. *Manage Learn* 1999; **30**(2): 141–57.

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11 Reason P, Bradbury H. Introduction: inquiry and participation in search of a world worthy of human aspiration. In Reason P, Bradbury H eds. *Handbook of action research: participative inquiry and practice*. Sage, 2001: 1–14.
12 Hopkinson J, Wright D, Corner J. Seeking new methodology for palliative care research: challenging assumptions about studying people who are approaching the end of life. *Palliat Med* 2005; **19**: 532–37.
13 Stevens T, Wilde D, Hunt J, *et al*. Overcoming the challenges to consumer involvement in cancer research. *Health Expect* 2003; **6**: 81–88.
14 Oliver S, Clarke-Jones L, Rees R, *et al*. Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach. *Health Technol Assess* 2004; **8**(15): 1–148.
15 Kreuger R. *Focus groups: a practical guide for applied research*. Sage, 1994.
16 Morgan D. *Focus groups as qualitative research*. Sage, 1988.
17 Stewart D, Shamdasani P. *Focus groups: theory and practice*. Sage, 1990.

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